



## Frequently Asked Questions

### GENERAL

**Q: What is the Long-Term Data Cooperative?**

A. The Long-Term Care (LTC) Data Cooperative is a provider-led effort that assembles electronic health record (EHR) data across geographically and structurally diverse skilled nursing facilities and residents. Our mission is to improve the quality of care within long-term care by translating comprehensive data on post-acute and long-term care residents nationwide into accessible and actionable information for clinicians, managers, and policy-makers.

**Q: Which Electronic Medical Records (EMR) companies are participating?**

A. We currently have agreements with American Health Tech (AHT), MatrixCare, and PointClickCare (PCC). Please note that you do not have to use one of these EMR vendors to enroll, and we are always looking for additional EMR vendors to join.

**Q. Can assisted living communities participate?**

A. Currently, assisted living communities are not able to participate, but we hope to include them in the future.

**Q: What are the goals of the Long-Term Care Data Cooperative?**

A: The database will be used for three broader purposes:

- (1) To provide reports back to enrolled providers that can assist them with clinical care and operations. These may take the form of quality measure reports with comparative benchmarks, resident-at-risk profiles, or reports to help with your discussions with managed care organizations. The content of the reports is suggested by enrolled organizations and are designed to complement or fill gaps in existing reports available from other sources.
- (2) Provide public health monitoring such as the prevalence of multi-drug-resistant organisms or respiratory viral infections, including influenza or COVID-19, that will be securely shared with the Food and Drug Administration or the Centers for Disease and Control and Prevention.
- (3) Provide data for academic researchers with non-commercial funding to conduct effectiveness research, which is research that looks at how well different treatments or care practices can improve resident outcomes. A provider-led committee determines whether an application to use these data for research can move forward.

**Q. Who is overseeing and running the LTC Data Cooperative?**

A. The LTC Data Cooperative is a provider-led effort governed by the American Health Care Association, with funding from the National Institute of Aging (NIA) through the [IMPACT Collaboratory](#). An Advisory Committee comprised of AHCA Board members, AHCA committee participants, providers at large, EMR vendors, and academic researchers provides advice and input on major decisions. Researcher access to the data is granted by the LTC Data Cooperative Research Review Committee with input from providers. Input from enrolled organizations is also sought prior to major decisions or changes.

**Q: Whom do I contact if I have questions?**

A. Please contact [LTCDDataCooperative@AHCA.org](mailto:LTCDDataCooperative@AHCA.org) with general questions. A representative will respond within 24-48 hours. For data and security questions, please contact Exponent, Inc. at [LTCD@Exponent.com](mailto:LTCD@Exponent.com).

## **BENEFITS**

**Q: What do I get from joining?**

A. Enrolled providers will receive free, customized provider feedback reports to help with clinical care or operations. These reports will be developed with input from enrolled providers and may include quality measures (existing and new), at risk resident profiles (such as hospitalization, falls, adverse events from medications), antibiotic stewardship, information to help with your discussions with insurance companies, and benchmarks of peers and care practice profiles such as use of antivirals for COVID-19 positive residents. Provider feedback reports are intended to complement existing reports available from other sources and are developed with input from enrolled organizations.

**Q. How does this help the long-term care community?**

A. A major barrier to developing appropriate clinical and operational responses during the COVID-19 pandemic was the lack of evidence on what works. We need more real-time data to rapidly answer these types of questions. In addition, many of the clinical decisions, treatments and practices in skilled nursing facilities are based on evidence from younger individuals or healthier elderly people living in the community. We need to understand what works and does not work for people who use long-term care services. Also, risk profiles can help better target residents who need different care, but most risk assessments used were not developed in long-term care populations. The LTC Data Cooperative will provide a comprehensive data set for academic researchers to help answer these questions.

**Q: How is the database beneficial to providers, medical and health care professionals, patients, and the community?**

A. This database will allow public health experts to examine how the vaccines and other treatments are working across long-term care residents. Those providing treatment to patients will be able to use the data to evaluate treatment plans for patients that have similar health conditions and concerns.

**Q. How does this help with public health surveillance?**

- A. The rapid detection and spread of multi-drug resistant organisms (e.g., *Candida auris*) is needed to help better inform timelier and tailored public health recommendations. The LTC Data Cooperative will help with surveillance of the spread of infections in a much timelier and more comprehensive manner than currently possible.

## PARTICIPATION REQUIREMENTS

### **Q. Are facilities or staff required to do anything after enrolling?**

- A. No, there are no expectations for enrolled facilities or staff to do anything. The parent organization does need to identify a primary contact that LTC Data Cooperative staff can communicate with and share facility-level provider reports. There is no requirement that the provider reports be used. We do ask that you keep us informed of any new facilities that you acquire or sell. There are opportunities to participate in various committees and groups, as well as review and provide feedback on researcher applications, but participation is voluntary and not required.

### **Q. Do we have to participate in research?**

- A. All research opportunities that involve participation by the facility (e.g., evaluating which of two different treatments work better or how a staff educational program improves resident outcomes) are voluntary and participation is never required. Research done by the researcher that only analyzes data is approved by the Research Review Committee after seeking voluntary input from all enrolled organizations.

### **Q: How much insurance coverage should an organization have?**

- A. The LTC Data Cooperative has a cap of \$100,000 should an organization have any culpability in any data breaches. Please email us at [LTCDataCooperative@AHCA.org](mailto:LTCDataCooperative@AHCA.org) if you have more specific questions regarding insurance.

## DATA COLLECTION

### **Q. What data is collected from my EMR?**

- A. The goal is to collect all the clinical information in the EMR, but the actual data transfer is dependent on the technology and structure of each EMR.

### **Q. How frequently is our data transferred?**

- A. This will depend on the type of EMR used; and varies from daily to monthly.

### **Q: Will any of our data be stored outside the United States?**

- A. No, data will only be stored in the United States.

### **Q: Will data be returned to the organization if the contract is terminated?**

- A. The data will not be returned. It will remain within the LTC Data Cooperative enclave,

however no further transmission from the date of contract termination will be transmitted.

## ENROLLMENT

**Q. Do I need to sign a business associate agreement (BAA) to participate?**

A. Yes, a BAA is required to enroll.

**Q: What forms do I need to enroll?**

A. Your organization will need to complete and submit the required legal agreements, which include a participation agreement, business associate agreement and authorization form to your EMR vendor to share data with us. You can receive copies of these documents by emailing [LTCDataCooperative@AHCA.org](mailto:LTCDataCooperative@AHCA.org) . You will receive a confirmation email within 72 hours of receipt. Once all parties have signed the legal agreements the data release form will be sent to your EMR Vendor to begin the data transferring process.

**Q: Who should I contact for assistance with enrolling?**

A. Please contact us at [LTCDataCooperative@AHCA.org](mailto:LTCDataCooperative@AHCA.org) . A representative will respond as soon as possible but no later than 24-48 business hours.

**Q: How do I know if my organization is eligible to participate in this data cooperative?**

A. All organizations with skilled nursing facilities are eligible to participate at no cost!

**Q: If my EMR vendor does not participate, can I still join this cooperative?**

A. Yes! You may participate in the data cooperative even if your EMR vendor does not choose to participate since EMR data is your data. Please complete all the steps to register. A team member from the LTC Data Cooperative will notify your EMR provider of your participation.

**Q: What are the next steps after completing the registration?**

A. You will receive a confirmation email once all requirements have been successfully submitted. The email will be sent to your appointed primary point of contact. The application will be reviewed by a LTC Data Cooperative team member to ensure all appropriate documents have been received and accurately completed. Your EMR provider will then be notified of your participation.

**Q: Do I need to reach out to my EMR vendor first?**

A. No! An LTC Data Cooperative team member will notify your EMR vendor of your participation. We currently have data transfer arrangements set up with AHT, MatrixCare and PCC.

**Q. Can I disenroll?**

A. Yes, you can disenroll at any time by emailing us at [LTCDataCooperative@AHCA.org](mailto:LTCDataCooperative@AHCA.org) . However, data that has already been transferred will continue to be used since removal would impact ongoing research and data reports.

**Q. How much does it cost to join?**

A. There is no cost for providers to join!

## **DATA ACCESS**

**Q: Who has access to the data?**

A. Data is stored securely by two contractors – Exponent and Acumen. The LTC Data Cooperative team can access these data to generate reports for participating organizations. Academic researchers who have received all the appropriate Institutional Review Board (IRB) approvals, and approval from the LTC Data Cooperative Research Review Committee on their research objectives, will be granted access. The data will not be downloadable or transferred to users but will be accessed through secure cloud-based research environment. Also, aggregate reports may be shared with public health agencies for surveillance and research evaluation purposes.

**Q: What access to our data do the other enrolled providers have?**

A. Other enrolled providers will not have access to any of your data. Enrolled providers only have access to aggregate reports specific to their facilities.

**Q. Will federal regulators or state licensing agencies have access to the data?**

A. No; neither Survey and Certification at Centers for Medicare & Medicaid Services (CMS) nor state licensing agencies of providers will have access to the data.

**Q. Can other individuals get access to the data such as hospital systems, insurance companies, etc.?**

A. No; only providers and approved academic researchers will have access to the data. Decisions on the use and sharing of data are made by the Advisory Committee, which is comprised of leaders from AHCA (board members, committee chairs/members), providers, and participating EMR companies.

**Q. Will my data be shared with (Health Information Exchanges) (HIEs) or other provider systems (e.g., such as hospital or physician EMR)?**

A. No; this data will not be shared with HIEs or other provider settings' EMRs.

**Q. Will my data be sold to others?**

A. No, the LTC Data Cooperative will NEVER sell your data. The data will be used for your benefit or for research that is federally-funded or otherwise non-commercial.

**Q: What steps will my organization need to complete to start the data-sharing process?**

A. There are no additional steps. The authorization you have provided in the Consortium Participation Agreements will be sent to your EMR provider.

**Q: Is there a tutorial on how to access the provider feedback reports?**

A. Not at this time, but there will be a secure portal that will allow access to the reports.

## SECURITY

### Q: How secure is the LTC Data Cooperative?

A. We take data security extremely seriously. The data is stored in a secure environment only accessible by LTC Data Cooperative staff. The data is converted into a usable database for use by academic researchers who access it only through a secure virtual environment, and cannot download it for any reason. For additional data and security questions, please contact Exponent, Inc. at [LTDCDC@Exponent.com](mailto:LTDCDC@Exponent.com).

### Q: What data security and protection does Exponent, Inc. provide?

A. Information security and data protection are cornerstones of the LTC Data Cooperative. Exponent Inc, which administers the database, demonstrates its commitment to these principles by adopting multiple industry-standard frameworks, such as:

- National Institute of Standards and Technology (NIST) Cybersecurity Framework (CSF), which serves as an overarching framework for understanding and communicating information cyber security.
- International Organization for Standardization (ISO) 9001:2015 (and others), which confirms Exponent's commitment to a robust, independently assessed quality management system.
- Amazon Web Services, which provides an encrypted HIPAA and HITECH-compliant environment in which data are stored and analyzed.
- Exponent will continue to uphold its commitment to quality, security, and privacy by adopting new and emerging risk management techniques as they are available. Should you require any additional detail, please email [LTDCDC@exponent.com](mailto:LTDCDC@exponent.com).

### Q: Does the vendor/other party complete a SSAE16 (SOC 1/2/3) Audit?

A. Please see the [Data Security Guide](#) for further information.

### Q: Is the software used to house data freeware?

A. Please see the [Data Security Guide](#) for further information. For additional questions, please email [LTDCDC@Exponent.com](mailto:LTDCDC@Exponent.com).

### Q: What are the number of User Licenses?

A. Data is only accessible by a member of the Exponent data science firm. No additional data licenses will be distributed.

## CONFIDENTIALITY AND CONSENT

### Q: How will resident confidentiality be protected?

A. All data is stored in a secure environment. All academic researchers requesting access must complete an application process, demonstrate proof of federal funding for research, as well as obtain Institutional Review Board (IRB) approval for human subject research with medical record information. Please contact [LTCDDataCooperative@AHCA.org](mailto:LTCDDataCooperative@AHCA.org) for more information.

### Q: Do I need to get consent from my residents?

A. Resident consent is not required since each enrolled organization will be signing a BAA

with the LTC Data Cooperative. For research uses, the need for consent will be decided by the Institutional Review Board (IRB) and will be the responsibility of the researcher to obtain. For research projects that are solely analyzing data, a waiver of consent is commonly granted. If research involves a new “intervention” (e.g., testing the effectiveness of a treatment), then consent is often required and will be the responsibility of the researcher to obtain. The Research Review Committee examines each application to make sure the appropriate IRB approvals and waivers are in place.

**Q. Will my organization’s name be publicly shared or mentioned in research?**

- A. The name of your organization will only be shared if you explicitly grant a researcher permission. All public reports, publications, or presentations will report data in aggregate and a form that should not allow identification of the participating organizations.